Striking a **New Balance**

PROPOSAL FOR A JOINT FEDERAL-PROVINCIAL/ TERRITORIAL DISABILITY SUPPORTS INVESTMENT INITIATIVE

PREPARED BY
L'INSTITUT ROEHER INSTITUTE

Striking a New Balance: Proposal for A Joint Federal- Provincial/Territorial Disability Supports Investment Initiative

Prepared by L' Institut Roeher Institute
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About

L'Institut ROEHER *Institute*

Canada's National Institute for the
Study of Public Policy Affecting
Persons with Intellectual
and Other Disabilities

L'INSTITUT ROEHER INSTITUTE IS CANADA'S POLICY RESEARCH ORGANIZATION promoting the equality, participation and self-determination of people with intellectual and other disabilities, by examining the causes of marginalization and by providing research, information and social development opportunities.

To fulfill this mandate, The Institute is engaged in many activities: research and public policy analysis; publishing; information gathering and dissemination; and training, education and leadership development.

The Institute acts as a centre for the development and exchange of ideas, all of which are founded on a new way of looking at disability in the context of a strong civil society. It critically examines issues related to the well-being and human rights of persons with disabilities. Based on its examination of these issues, The Institute raises awareness about the barriers that affect people's full participation in society and that prevent them from exercising their rights. The Institute also presents policy and program alternatives.

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SUMMARY OF PROPOSED INVESTMENT INITIATIVE

In 1998 the federal and provincial/territorial governments made the joint accord, ***In Unison: A Canadian Approach to Disability Issues***, to advance the full citizenship of people with disabilities based on the values of "equality, inclusion and independence."[1] The accord expresses commitment to principles of self-determination, autonomy, dignity, respect, participation and independent living. Three building blocks to realize citizenship are disability supports, employment, and income. The objectives and policy directions concerning disability supports are to:

- Improve access to disability supports
- Enhance the portability of these supports across regions and settings
- Provide greater assistance for disability costs
- Separate access to supports from eligibility for income and other programs
- Establish more consumer control, flexibility and responsiveness in the provision of disability supports

The Joint Federal-Provincial/Territorial Disability Supports Investment Initiative is a proposal to put these objectives and policy directions into action, to make them real for people with disabilities, their families, and communities. It recognizes that disability supports are foundational and integral to securing the other building blocks of *In Unison* – employment and secure income. It calls for a comprehensive, coordinated, inter-sectoral, multi-jurisdictional government initiative to invest in disability supports in a way that begins to deliver on the commitments they made in *In Unison* to advancing the full citizenship of people with disabilities in Canada.

The aim here is not to present detailed policy recommendations. Rather the purpose is to provide a common framework for governments and the disability community to move the disability supports policy agenda forward in a concerted and strategic manner.[2]

The proposal reflects findings of many years of consultation in the disability sector and many years of policy research. The proposed investments cannot all be made at once. The 'map' outlined in this proposal is meant to provide a strategic direction. We recognize that full implementation would proceed incrementally and would likely take place in 2-3 year period.

The directions outlined in this proposal fit well within the commitments made to joint social policy development by both levels of government, and to real dialogue and collaboration with the community and voluntary sectors. In addition, the national Voluntary Sector Initiative has helped to recognize key roles for the voluntary sector that need to be supported to advance common policy goals. In particular:

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[1] See Federal/Provincial/Territorial Ministers Responsible for Social Services, *In Unison: A Canadian Approach to Disability Issues* (Ottawa: Human Resources Development Canada, 1998). All governments except Quebec signed the accord. The Government of Quebec expressed its commitment to the vision and principles of the accord.

[2] This proposal has been revised from earlier versions, and reflects ongoing input from disability community organizations. The basic framework for the initiative has remained consistent throughout the drafts. This document includes a section on costing the extent of unmet needs for supports.

- *In Unison* notes that to secure the overall goal of full citizenship for people with disabilities, community development in all sectors and a "healthy infrastructure of disability organizations" is needed - government policy on its own cannot achieve the policy goal.[3]

- The *Social Union Framework Agreement* notes the important role played by community organizations in developing social policies and delivering programs; one of the stated principles of the *Agreement* is that both levels of government "work in partnership with individuals, families, communities, voluntary organizations, business and labour, and ensure appropriate opportunities for Canadians to have meaningful input into social policies and programs."[4]

- "Working Together", a recent report on the voluntary sector, cites four key roles played by the over 175,000 non-profit community organizations across Canada, many of which deliver disability-related supports: they provide a vehicle for public policy dialogue, deliver government-funded and other services, engage citizens "in the building of communities", and build links across diverse communities, cultures, regions, and with other nations[5]. The report's recommendations are designed to strengthen the capacity of these organizations - locally, provincially/ territorially and nationally.

The joint investment initiative seeks to deliver on the broad commitments in these agreements and reports, in a way that would effectively engage the disability community. The initiative would entail:

I. Shared Understanding of Key Terms and Policy Issues
II. Commitments by All Levels of Government
III. Areas for Action -- New Transfers by Federal and Provincial/Territorial Governments to:
   - Individuals
   - Families
   - Communities
IV. Foundational Principles
V. Monitoring and Tracking
VI. Reporting on Outcomes
VII. A Joint Financial Investment

A final section of this paper, provides a very preliminary analysis of the scale of costs of unmet need for disability supports, and the kinds of investments that would help to 'strike a new balance' between private costs/burdens, and public support to advance the full citizenship of people with disabilities. The proposal was written by Michael Bach, Mary Anne Burke and Cameron Crawford of The Roeher Institute.

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[3] See *In Unison*.
[4] See *A Framework to Improve the Social Union For Canadians: An Agreement between the Government of Canada and the Governments of the Provinces and Territories, February 4, 1999.*
[5] Canada, *Working Together: A Government of Canada/Voluntary Sector Joint Initiative* (Ottawa: Voluntary Sector Task Force, Privy Council Office, Government of Canada, 1999).

I. Shared Understanding of Key Terms and Policy Issues

Disability means:
There are many ways of defining disability. For the purpose of this proposal we define disability as limitations in carrying out daily activities and in participating in social, economic, cultural, and political life. Limitations may arise from:

- A physical, sensory, intellectual, emotional or other personal condition/characteristic
- Societal stereotypes about such human conditions
- Ways of organizing social, economic, and built environments that exclude or impede participation

Disability Supports include:
Personal

- Personal support for everyday activities
- Planning and coordination supports
- Aids and devices
- Modified environments specific to the individual person
- Medications
- Therapeutic services
- Transportation measures specific to the needs of the individual person (e.g. modified personal vehicle)

Family

- Respite services
- Compensation for caregiving
- Work-leave protection and benefits
- Access to retirement pensions for those who leave the labour force to provide informal support
- Access to health benefits for those who provide support and who lack adequate insurance coverage
- Planning and coordination supports
- Counseling and other therapeutic supports

Community

- Human capacity in community organizations and services to include people
- Training and information to strengthen human capacity

'Disability Supports Systems' vary from community to community and across provinces/territories, but generally include 3 main components:

- Individuals – 4.2 million, among whom about one-third have out-of-pocket expenses for disability supports.
- Family members – 2.3 million who provide supports (including 500,000 who have disabilities themselves), among whom almost half have out-of-pocket expenses, and among whom over half indicate they need more back-up supports to continue providing assistance.

- Community service providers, including: specialized services (425,000 who provide daily living assistance and among whom almost 40% personally incur out-of-pocket expenses in providing disability supports; many thousands more provide therapeutic, developmental, communication and other specialized services); and generic community services (health care, education, recreation, public services).

The bulk of disability supports is provided on a voluntary, unpaid basis by family members, including people with disabilities themselves. The current balance of responsibility between public investment, voluntary care and expenditure, and community capacity is not working. A new balance is needed to ensure that individuals have access to needed supports; that family members are able to obtain back-up supports they require; and that generic and specialized community services do develop resources and capacities. Research clearly shows that without a re-consideration of the balance of investments, the full citizenship of people with disabilities and their family supporters is vulnerable.

A joint investment strategy would address the following key issues:

For Persons
- Ineffective system for needs identification, assessment, planning and coordination
- Restrictive eligibility
- Lack of access to needed supports – in home, community, developmental, school, and employment
- Supports that are available are often unresponsive to individual needs, circumstances and self-determination
- Unaffordable supports

For Families
- Contributions families make go unrecognized and unsupported
- Inflexible eligibility
- Inadequate supports – respite, in-home, community access, employment-related
- Heavy cost burden – high poverty rates

For Communities
- Non-inclusive mainstream services
- Lack of accountability for inclusion and citizenship by community sectors
- Inadequate investment in human resource development
- Lack of systematic strategy for deinstitutionalization

II. Commitments by all Levels of Government

Under the ***Joint Disability Supports Investment Initiative*** all levels of government would commit to:

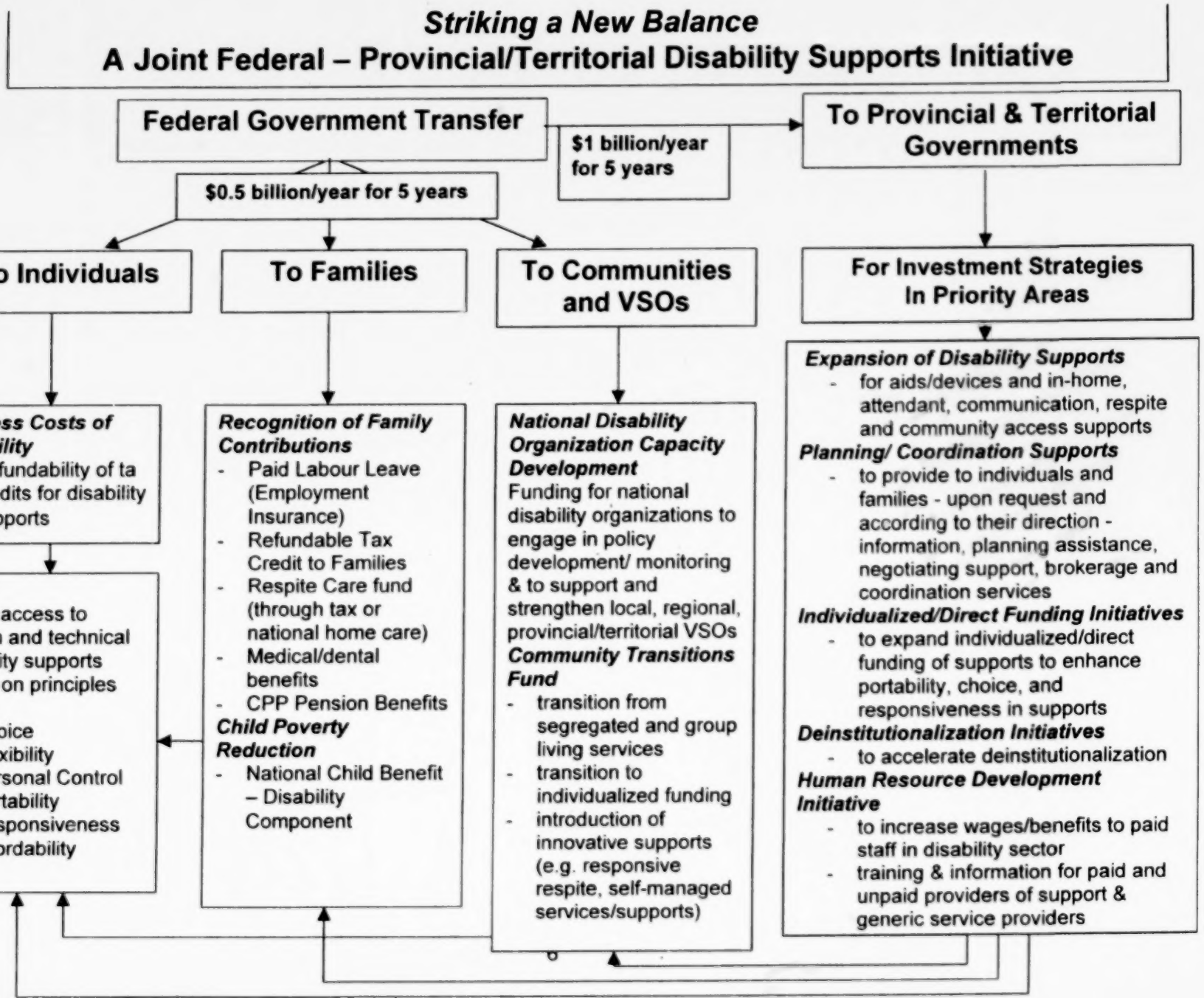
- Enhancing access to disability supports and services
- Monitoring and tracking investments; and
- Reporting on outcomes for the health and development of people with disabilities, their families and for the development of community capacities

Under this initiative, both levels of government would ***strike a new balance with individuals, families and communities*** in shouldering the costs and advancing the citizenship and social inclusion of people with disabilities.

- Provinces would agree to build on existing investments in disability supports and services with a new federal contribution, initially set at $1billion per year for five years.
- The federal government would agree to new investments in areas within their jurisdiction for persons with disabilities, families and communities initially set at $0.5 billion per year for five years.

III. Areas for Action

See chart on next page.


Striking a New Balance
A Joint Federal – Provincial/Territorial Disability Supports Initiative
Federal Government Transfer
$1 billion/year for 5 years
To Provincial & Territorial Governments
$0.5 billion/year for 5 years
To Individuals
To Families
To Communities and VSOs
For Investment Strategies In Priority Areas
Address Costs of Disability
- Refundability of ta credits for disability supports
For:
Better access to human and technical disability supports based on principles of:
- Choice
- Flexibility
- Personal Control
- Portability
- Responsiveness
- Affordability
Recognition of Family Contributions
- Paid Labour Leave (Employment Insurance)
- Refundable Tax Credit to Families
- Respite Care fund (through tax or national home care)
- Medical/dental benefits
- CPP Pension Benefits
Child Poverty Reduction
- National Child Benefit – Disability Component
National Disability Organization Capacity Development
Funding for national disability organizations to engage in policy development/ monitoring & to support and strengthen local, regional, provincial/territorial VSOs
Community Transitions Fund
- transition from segregated and group living services
- transition to individualized funding
- introduction of innovative supports (e.g. responsive respite, self-managed services/supports)
Expansion of Disability Supports
- for aids/devices and in-home, attendant, communication, respite and community access supports
Planning/ Coordination Supports
- to provide to individuals and families - upon request and according to their direction - information, planning assistance, negotiating support, brokerage and coordination services
Individualized/Direct Funding Initiatives
- to expand individualized/direct funding of supports to enhance portability, choice, and responsiveness in supports
Deinstitutionalization Initiatives
- to accelerate deinstitutionalization
Human Resource Development Initiative
- to increase wages/benefits to paid staff in disability sector
- training & information for paid and unpaid providers of support & generic service providers

A. Federal transfer to persons with disabilities

To better offset the direct and indirect costs of disability to individuals, particularly for people with lower incomes, refundable tax credits would be available for disability supports and for the hidden general costs of disability. These measures would replace the present system of nonrefundable credits. Federal/provincial/territorial agreements would ensure that any refundable credits result in a net benefit to the eligible claimant (i.e. income would not be "clawed back" from other measures such as the social assistance of people who are not working at paid employment).

In themselves, the refundable tax credits for costs associated with disability would likely not come close to addressing the full costs to individuals. Further program measures at the provincial/territorial level are needed in this regard and are discussed below.

The federal government also has a major role to play in ensuring income security for people with disabilities through the Canada Pension Plan and Employment Insurance and labour market development initiatives. While this proposal for disability supports does not directly address these important policy issues, better access to disability supports is a key condition for education and employment that ultimately lead to adequate incomes.

B. Federal transfer to family members providing support to persons with disabilities

Proposed measures would require detailed policy and program consideration and development. Funds under this transfer serve two primary aims: compensation for supports provided by families; and child poverty reduction.

1. Compensation for informal providers of support gives formal recognition to the role many family members and other informal providers play as the backbone of the disability support system. The transfers would address their associated needs, and would include:

- **Paid Employment Leave**. Income lost from paid employment due to informal assistance provided would be offset through the Employment Insurance (EI) Program;
- **Refundable Disability-related Tax Credits.** The difficult to itemize out of pocket costs, indirect costs such as lower employment incomes, and the direct cost of items purchased to address the disability-related needs of a family member would be offset through refundable tax credits. Enhanced and expanded disability-supports programs administered by provincial/territorial governments would further reduce the financial burden experienced by family members in the purchase of disability-related supports;
- **Respite Care for Vacation and Emergency Days**. Family members who provide direct support because of disability would have access to four weeks annual respite care, in lieu of vacation leave and for emergency respite care for sick or disability days taken by informal providers on as-needed basis, administered through a National Home Care Strategy, or with benefits

delivered through the tax system;

- **CPP Retirement Pension Benefits**. To recognize the value of contributions made by family members who provide informal support, for every year spent out of the full-time labour force providing support, they would be able to accumulate one pensionable year towards a CPP retirement pension. Eligibility would be determined through the same mechanism as for receipt of disability caregiver credits through the tax system and pensions would be administered through CPP; and
- **Medical and Dental Benefits** would be available for those not covered by other plans. Eligibility would be determined through the same mechanism as for receipt of disability caregiver credits through the tax system.

2. Child poverty reduction. Children with disabilities are over-represented in low-income families. Income-tested measures would be put in to place to provide a degree of cash compensation to parents with middle and low incomes for the additional costs associated with the care and nurturing of a child with disabilities. Eligibility would be determined through the same mechanism as for receipt of disability care giver credits through the tax system. Transfers to individuals would take the form of a **Child Disability Benefit**, administered through the tax system under the *National Child Benefit Program*. Agreements would be struck between federal and provincial/territorial governments to ensure that those who qualify for the Child Disability Benefit actually receive a net benefit (i.e., there would be provisions to safeguard against "claw back" from parents on social assistance),

C. Federal Transfer to Communities

This transfer gives recognition to the essential role local communities and voluntary-sector organizations play in ensuring the inclusion and full citizenship of persons with disabilities. It would support innovative best practice models that emerge from grass roots community initiatives.[6] Measures to be funded under this federal transfer would include:

- **Grants to Disability Sector NGOs**. Under the National Voluntary Sector Initiative, funding could be provided to national, regional and local disability organizations to strengthen their capacity to engage in public education, to develop technical capacity in the voluntary sector (e.g. to strengthen the skills of persons with disabilities and other partners in the community such as employers), and to participate effectively in the public policy process.

- **Community Transitions Fund**. This fund would enable federal transfers to local community sectors and partnerships to assist in the process of

[6] The transfers *would not* be targeted to addressing the enormous systemic barriers at the community level such as the need to retrofit transportation, modify architecture so that places of learning and work are more accessible, upgrading technology in schools, libraries etc. for greater access b persons with disabilities. An inclusive infrastructure initiative is required to address long-standing obstacles to full inclusion, and to newly emerging issues along the information highway.

transitioning from segregated, institutionalized and other congregate services to more individualized, self-directed, and responsive approaches;

D. Transfer to Provinces and Territories and Provincial/Territorial Contribution

Federal funds transferred under this initiative plus new dollars contributed by Provinces and Territories would be invested in priority areas. Within each province and territory governments, the disability community and other community partners would sit down together to work out the particular policy mix and program strategy that would best meet priority needs.

Investment strategies would include:

- **Expansion of Disability Supports Programs** The infusion of federal money would help offset costs to provinces associated with the provision of a range of supports including: attendant services, home-making services and personal assistance; aids and devices, including home adaptations, medical supplies and supports for complex medical needs; respite care, including in-home and out-of-home for short-term or emergency support; and developmental services such as audiology, speech and language services, vision services, physiotherapy, occupational therapy, etc.;
- **Planning/Coordination Supports**. Funds would be available to help develop and ensure universal availability of supports and services to assist with needs identification, personal planning, coordination of supports, etc. These supports would be available to persons with disabilities and to family members providing support on an as requested basis, and would be delivered under their direction.
- **Individualized/Direct Funding.** Funds would provide opportunities to explore and expand innovative individualized and direct funding options. These options would be developed consistent with principles of portability, flexibility, responsiveness, choice, control, and social and economic inclusion.
- **Deinstitutionalisation Initiative**. Funds would assist provinces and territories to accelerate their deinstitutionalisation initiatives, with the eventual goal of supported family-based care for children with disabilities and supported, independent community living for adults with disabilities.
- **Human Resource Development Initiative**. Provinces and territories could invest funds in strengthening the training and information resources of formal and informal disability support workers. While funds could also be used to make real collective bargaining arrangements that seek better job security and adequacy of earnings in the disability sector, the federal transfer to provinces would not be used primarily for this purpose; in the interests of expanding the supply of supports, such investments should constitute only a minority of funds transferred and invested.

IV. Foundational Principles

In pursuing these areas for action, the following principles would be followed. Transfers and investments would ensure that:

- Any new investments will achieve a significant net benefit to advance the citizenship of persons with disabilities and family members who provide support, and will be monitored for accountability to that outcome; all funds transferred by the federal government will be used to enhance current investments by provincial and territorial governments.
- As agreed to by provinces/territories in *In Unison*, access to supports will be based on need and will not depend on eligibility for income support and other programs.
- Transfers to individuals to assist in meeting the costs of disability supports will not be means tested, nor considered income for the purpose of taxation or for determining need for financial assistance to meet basic needs (e.g. for food, shelter, utilities, etc).
- Planning and other supports will be accountable to, respectful of and subject to the control of persons with disabilities. Family supports will be accountable to, respectful of and subject to the control of family members who use such supports.
- Supports for individuals and for families will be personalised, coordinated, comprehensive, flexible and portable.
- The majority of funds transferred will be invested in expanding the supply of disability supports for children, youth, and adults with disabilities.
- The disability community will be engaged in an active, significant role in policy development, in guiding implementation activities, in designing the accountability framework, and in monitoring outcomes.
- Provinces, territories and communities will have the scope to innovate and meet regional priorities while pursuing a common set of principles and directions;
- Collaboration and partnerships will be fostered among governments, government departments, and sectors of society.

V. Monitoring and Tracking Investments

Investments would be monitored against outcomes agreed to by all parties involved. Agreed upon outcomes – that are consistent with the citizenship and inclusion principles of *In Unison* – would be integral to the agreement. The initial level of public investment would be adjusted and fine-tuned according to the evidence that emerges from an ongoing monitoring and evaluation process. Monitoring is not a new idea. It is now recognized as an essential tool to ensure that public investments result in intended outcomes. SUFA, the NCA , ECDI and *In Unison* each commit to monitoring and public accountability for results-based management.

VI. Reporting on Outcomes

In keeping with the principles of transparency and public accountability, regular reports will be made on investments, process and outcomes under the Joint F/P/T Disability Supports Investment Initiative. The reports would engage all parties concerned, enabling persons with disabilities, family members, governments and the larger civil society to fully participate as equal partners in evaluating investments, highlighting successes and identifying opportunities to address remaining challenges.

VII. A Joint Financial Investment

This proposal suggests that a *joint* investment strategy by both levels of government is needed to 'strike a new balance' in the resourcing of disability supports in Canada. The proposal suggests that an initial investment of $1.5 billion per year for five years by the federal government would make a significant difference in addressing the unmet needs for support among individuals, families, and communities. Such an investment could be structured as follows:

- A $1 billion transfer to provincial and territorial governments to enhance their capacity to address priority issues in disability supports
- An investment of $0.5 billion per year for five years directly to persons with disabilities and families to assist them in cost neutral access to needed supports and services and to communities to make needed transitions and restructure community service systems to deliver on the commitments of *In Unison* – to increase flexibility, portability, and responsiveness in supports.

Provinces and territories would make additional investments in disability supports – through reinvestment strategies on any savings realized from the new federal transfer. Provinces/territories would retain the prerogative to make any additional expenditures they consider necessary and sustainable for meeting priority needs.

As well, the proposal points to the usefulness of a federal transfer to individuals and families through the tax system, Employment Insurance, the Canada Pension Plan, and through other financing tools – such as a national homecare strategy if that is designed and implemented. Detailed costing projections for these investments need to be developed. The initial $0.5 billion signals a significant commitment.

VIII. How Much Will This Cost?

Costing the investments required to strengthen the disability supports system is a complex task. Below, we provide a few ways to cost supports needed, based on available data. Others ways of costing might be designed. More detailed work is required to more accurately gauge the level of expenditure undertaken by individuals and their families. Available data suggests that significant investments are required –

not to fully fund the cost of needed supports – but to help strike a more workable balance with individuals, families and communities.

Increasing the Availability of Publicly-Financed, Provincially-Regulated, Paid Personal Supports

Analysis of the 1991 HALS found that, of the 1.854 million adults with disabilities who needed help with everyday activities (52.5 per cent of all adults with disabilities), only 89,000 had needs that were fully met and were receiving help from community agencies at no net cost to themselves. These were people who had no direct service costs for the agency-based supports they received, or had costs that were fully reimbursed through public programs or private plans. Those with fully met needs at no net cost to themselves represented only 4.8 per cent of those needing help with everyday activities.

We have estimated on the basis of the National Population Health Survey of 1998 that support in everyday activities was needed by a further 204,000 children younger than 15 years of age (i.e., 389,000 children with disabilities times 52.5 per cent). It is conceivable that children with disabilities may be twice as well protected as adults against inadequate levels of support at no net cost to themselves or their families (i.e., they receive all the support they need at no net cost in about 10 per cent of cases). Assuming this to be the case, about 20,000 children's needs are fully underwritten by public programs and private plans.

What level of investment in agency-based services would help to close the gap between the need for support and the availability of even marginally better levels of full support from services beyond the family at no net cost to individuals with disabilities or their families?

The research found that, in 1996, 425,000 people were helping others (children and adults) with disabilities through agencies. Where employment was the main source of income of those helping, their estimated average wage was $24,262 for the year. The product of these two figures yields a total estimated salary cost for agency-based help of $10.311 billion (adjusted by the Consumer Price Index to $11.051 billion in year 2000 dollars). In order to close the gap between people's need for support and the availability of fully-funded support, the total investment in paid support could be increased by a modest ten per cent, or by about $1.105 billion.

This amount is quite conservative as it does not factor into the picture the need for more specialist services such speech therapy, physiotherapy, occupational therapy, counseling, service-planning and coordination, sign language interpretation, Braille training and various other services that are specific to disability. Such services involve more than the provision of help with everyday activities, fall within provincial/territorial jurisdiction, but are usually beyond the scope of publicly-insured health care services. There is no assurance that such essential services to people with disabilities will be available to those who need them at little or no direct charge to individuals or families.

Offsetting Costs to Individuals

Direct Costs

Owing to the lack of credible, broadly-based statistical data, it has been problematic to estimate the direct cost to individuals of the services, technologies and other items they require because of their disabilities. However, it is known on the basis of HALS that, in 1991, 34 per cent of adults with disabilities incurred out-of-pocket expenses that were not reimbursed by any public program or private plan. The same was true for 37.6 per cent of children with disabilities. If we use the 1998 NPHS figures for the number of people with disabilities, and assume that the percentages with out-of-pocket expenses in 1991 applied in 1998, an estimated 1.458 million children and adults had out-of-pocket expenses for disability-specific services and items.

The Department of Finance (1991)[7] released an estimate of $1,160 per person on average (in 1989 dollars) where individuals incurred disability-specific expenses. The figure was based on HALS 1986. More recent statistical data from Statistics Canada on costs relating to disability have not been released. Assuming that the 1989 estimate continues to apply in general terms in the year 2000, the figure adjusted by the Consumer Price Index is $1,569 per person incurring expenses. The total estimated out-of-pocket costs are in the range of $2.287 billion.

If individuals were to be reimbursed only 10% of this contribution, the contribution by governments and private plans would amount to $229 million.

Indirect Costs

Health Canada (1997)[8] recently reported that the cost of long-term disability in terms of lost productivity to the Canadian economy in 1993 was $38.3 billion. This figure represents the economic value of days lost from the economy owing to long-term disability. The Gross Domestic Product that year was $724.9 billion[9]. Long-term disability represented about 5.3 % of the GDP that year.

This cost is one that accrues not only to the economy in general, but to individuals with disabilities and their families in particular. We are not addressing this issue, other than to point out that effective measures are required re-integrate back into the productive labour force people who become disabled, whether through disease and illness,

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[7] Disability Tax Credit: Evaluation of Recent Experience". Department of Finance. Canada. December 1991

[8] Health Canada (1997). Economic Burden of Illness in Canada, 1993. Ottawa: Minister of Public Works and Government Services.

[9] Source: Statistics Canada, CANSIM, Matrix 6547.

accidents at work, accidents at home, traffic accidents, factors related to aging or other causes.

Offsetting Direct Costs to Families

Our research has found, on the basis of the General Social Survey Cycle 11, that 2.253 million people helped family members with everyday tasks because of disability in 1996. Those helped because of disability are mainly parents (44.3 per cent), followed next by spouses/partners (30.3 per cent). Sons/daughters and siblings form a significant but less sizeable proportion (16.7 per cent in total). Grandparents are next (5.4 per cent), followed by uncles, aunts, cousins and nephews (3.3 per cent).

Of those people who provided help, 1.658 million reported the amount of time they invested in the reference year in providing such help. Presumably the remainder were unable to estimate how much time they invested, or simply did not provide such information for other reasons.

We took the 1.658 million people who did provide figures for the amount of time they invested in helping, and found that they provided 316 hours of help per year on average. This works out to about 524,287,000 person hours of assistance. The estimated hourly cost of wages for agency-based help to people with disabilities in year 2000 dollars is $15.76. The total value of the help provided by family members in present dollars, then, is about $8.3 billion. Some 1.054 million of these people had additional expenses as a result of helping family members with disabilities. While they were providing an estimated $6.244 billion worth of support, there are no broadly-based statistical data on the level of out-of-pocket expenditure these family members incurred.

No one is suggesting that these costs should be fully reimbursed. However it is reasonable to advance the notion that, in view of the major value of the supports provided and that additional expenses are incurred in many instances, some measure of financial relief for families would be welcomed.

In fact, some 358,000 family members indicated in the GSS that this is the case. These people provided 519 hours of help per year on average to their family members. The estimated economic value of this help was about $2.933 billion. If only 10 per cent of this contribution was more directly recognized through cash transfers, tax relief, more flexible EI coverage and other measures, $293 million in additional funding would be available to families.